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# Talking about suicide: Confidentiality and anonymity in qualitative research

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## Abstract

While it is acknowledged that there is a need for more qualitative research on suicide, it is also clear that the ethics of undertaking such research need to be addressed. This article uses the case study of the authors' experience of gaining ethics approval for a research project that asks people what it is like to feel suicidal to (a) analyse the limits of confidentiality and anonymity and (b) consider the ways in which the process of ethics review can shape and constrain suicide research. This leads to a discussion of the ways in which ethics committees assess and monitor qualitative research more generally and some preliminary suggestions for how this might be improved.

## Keywords

Anonymity, confidentiality, ethics committee, qualitative research ethics, suicide, research ethics

## Introduction

While there is a wealth of research into suicide, there remains a lack of qualitative inquiry necessary for a more thorough understanding.<sup>1</sup> Furthermore, one of the perceived obstacles to addressing this gap is the difficulties qualitative researchers face in gaining ethics approval for studies involving people who are or have been suicidal.<sup>2</sup> From a nursing perspective, in addition to caring for patients who experience suicidal feelings, nurses might themselves be involved in researching suicide or helping to recruit participants to a study on suicide. Equally, a nurse might, as an ethics committee member, be asked to give ethical approval for such a study.

At the time of writing, the authors of this article are undertaking a study designed to elicit the first-person experience of feeling suicidal, with the aim of developing a theoretical model of suicidal feelings that will be used to help everyone to identify and offer empathic support to those who feel suicidal. The project – 'The Experience of Suicidal Feelings' (ESF) – is in two stages, the first of which is complete and the second of which is ongoing. The method combines a questionnaire with in-depth interviews and a grounded theory approach with philosophical phenomenology. The focal point of the Stage 1 questionnaire is the open-ended question 'What is it like to feel suicidal?', and participants (most of whom completed the questionnaire

online) were invited to write as much or as little as they chose in response. Stage 2 consists of interviews with some of the people who completed the questionnaire, exploring in more depth the main themes that emerged from the initial analysis of this data. Interviews are conducted face-to-face, by telephone or by email, depending on the preference of the participant.

## **Ethics and qualitative research in suicide**

While qualitative research does not pose the risk of physical harm associated with some medical research, it would be a mistake to think that it is risk free. Being interviewed, for example, often at length, in depth and on a sensitive topic, can be experienced as intrusive and distressing. Added to this, the relationship that develops between the researcher and the participants brings with it additional ethical demands, especially insofar as it can share some features of a therapeutic relationship.<sup>3</sup> Thus, the boundaries of the relationship require careful negotiation and perhaps renegotiation, with particular attention paid to the ending of the relationship, both the timing and the manner in which it is ended.<sup>4</sup> Nor are the ethical issues confined to the process of data collection; further ethical issues arise in the process of analysis and publication, for example, with regard to the way in which participants are portrayed, and to protecting anonymity while presenting the data in a way that is accurate and sufficiently detailed.<sup>5-7</sup>

As in medical research, the principles of informed consent and confidentiality protect the dignity and rights of the participant and minimise the risk of harm. However, qualitative research design is often 'emergent': in ESF, the Stage 2 interviews are based on the Stage 1 questionnaire data with the content of the later interviews evolving further as the themes emerge from earlier interviews. This means that the direction of qualitative research is to some extent unforeseeable and the risks to the participant are therefore more difficult to establish before the study begins.<sup>3,5,8</sup> Added to this, given that the extent to which an interview topic is likely to be experienced as distressing is subjective, the participant's ability to assess the level of risk in advance is limited.<sup>9</sup>

This limitation on available information is further compounded by the relative lack of research into the experience of taking part in research on suicide. What evidence there is suggests that while there is a small but not insignificant risk that reflecting on suicidal feelings will cause the individual to revisit those feelings, it is unlikely that this will be experienced as more than momentary discomfort.<sup>10</sup> It also appears unlikely that negative feelings experienced while participating in a study lead to behavioural change.<sup>11</sup> This is supported by the findings of Smith et al. In a clinical study comparing physiological changes in suicide ideators and suicide attempters, which involved questioning participants about suicide and psychiatric symptoms and exposing them to suicide-related images, follow-up interviews were conducted at 1 and 3 months after participation in the study. Participants were asked whether they had experienced any change in the degree of suicide ideation and thoughts about death, and whether they had attempted suicide or engaged in self-harm since participating in the study. In both of the follow-up interviews, no participant reported an increase in suicide ideation, and neither did anyone report having attempted suicide or engaging in self-harm. Finally, some participants reported a reduction in suicide ideation, and several commented that participating in the study had enabled them to discuss problems for the first time;<sup>12</sup> that there can be benefits to taking part in research is further supported by evidence from studies with other vulnerable populations.<sup>13,14</sup>

In part to address this lack of available evidence, the research design for ESF includes first, an impact evaluation questionnaire, which asks participants to rate their mental state immediately before and after taking part, and second, the opportunity for participants to provide feedback on their experience of taking part. The purpose here is twofold: first, to monitor the well-being of participants while in the study and to encourage them to monitor themselves, and second, to gain further understanding of the impact of the research on participants, which will be used to inform future studies.

In addition to ensuring adequacy of information, there is also the question of capacity to consent. As might be expected, some participants in the study have a psychiatric diagnosis and while a psychiatric diagnosis is not by itself an indication of lack of capacity to consent to participate in research,<sup>3</sup> and again there is a lack of evidence regarding the relationship between suicide risk and competency to consent to participate in research,<sup>15</sup> nevertheless there are circumstances under which consent may be compromised.<sup>16</sup> This requires additional vigilance, for example, paying attention to participant's reasons for taking part and regularly revisiting consent, although it might be argued that this is a requirement for all qualitative research. In other words, a psychiatric diagnosis and a relatively high risk of suicide are just part of the context within which informed consent is negotiated.<sup>2</sup> In particular, there is a relationship between the sensitivity of the topic in qualitative research and participant vulnerability;<sup>17</sup> and while participant vulnerability does not entail lack of capacity, it is a factor in assessing whether choices are substantially autonomous.<sup>3,17,18</sup> Thus, the impact of both a psychiatric diagnosis and the sensitivity of the topic in suicide research require ongoing attentiveness on the part of the researcher.

Like informed consent, a commitment to confidentiality is both essential and potentially problematic in qualitative research. On the one hand, confidentiality and anonymity are vital to ensure that the participant feels safe in revealing what is often personal information (and, as the ESF questionnaire data revealed, may never have been shared with anyone else). On the other hand, because of the nature of the research, it is possible that the participant will reveal something that gives the researcher a cause for concern. In a study of first-person perspectives on suicidal feelings, there is of course the possibility that the participant will reveal an intention to take their own life. It is necessary to consider, then, the extent of the commitment to confidentiality that can be offered to participants when they reveal this intention. This in turn raises more fundamental questions about the ethics of suicide, for example, whether suicide can ever be considered a rational choice and whether there is always an obligation or even a right to break confidentiality in order to prevent suicide.<sup>19–21</sup> The question of the limits of confidentiality will now be considered further in the context of an account of the process of gaining ethics approval for the study.

### **Case study – ‘The ESF’, confidentiality and ethics review**

Before beginning to recruit participants to the project, which is based in the United Kingdom, ethics approval was sought from the National Health Service (NHS).<sup>1</sup> The body responsible for NHS ethics approval is the National Research Ethics Service (NRES), which was at that time a part of the National Patient Safety Agency (NPAS).

In February 2010, approval was granted. However, because it was not possible to provide an interview topic guide before completing Stage 1 (since the results from Stage 1 would inform the content of the interviews), approval for Stage 2 was conditional on submitting a Substantial Amendment with the topic guide, together with details of the arrangements for the interviews.<sup>ii</sup>

To summarise briefly, the Substantial Amendment was submitted in December 2010 and after being considered by two separate Research Ethics Committees (RECs), approval to carry out the interviews was eventually granted in August 2011. However, it was granted only on the condition, and against the wishes of the researchers, that the commitment to participant confidentiality was substantially changed.

The original confidentiality statement, used in Stage 1 of the project, limited confidentiality only where required by a court order or where there was a threat of serious harm to others. However, it was explicitly stated that confidentiality would not be broken in cases where the participant revealed a plan for suicide, without their prior consent. Thus, while the researcher would follow a clear protocol to identify and respond in cases where a participant was considered to be at risk, this would stop short of doing anything, including contacting a health-care professional, without the participant's consent.

The amended confidentiality statement, included in the consent form and participant information sheet for Stage 2 of the study, is as follows:

When you give your consent to take part in Stage 2, we will ask you to provide us with your name, telephone number and address. We will also ask for the contact details for your G.P. or if more appropriate, for another health-care provider, such as your care coordinator or your CPN if you are currently accessing specialist mental health services. We will use these contact details only if we think that you are in immediate danger of making an attempt on your own life, and we would always tell you who we are contacting and seek your agreement (though we would have to make the call whether you give your consent or not).

That is, participants were asked to agree in advance to confidentiality being broken where there was perceived to be a risk of serious harm to self, whether or not they consented to this at the time.

In addition to extending the limits to the commitment to confidentiality, this also meant that it was no longer possible for a participant to take part in both stages of the study entirely anonymously. In the original proposal, it had been anticipated that this would be an option for participants choosing to take part by email, in which case the only contact details available to the researchers would be the email address. While still able to take part by email (the option chosen by the majority of participants in Stage 2), full contact details would have to be supplied.

This is significant since, while anonymity is rightly viewed as a component part of confidentiality, that is, as one means of protecting confidential information, in the context of research ethics, anonymity can also be considered separately. On the one hand, for some research participants, anonymity means invisibility. In qualitative research in particular, participants can take the view that they are co-authors of the research and deserve acknowledgement as such.<sup>6,22</sup> On the other hand, in suicide research, absolute anonymity might prove necessary to provide the conditions under which some people feel able to take part at all. Edgar has argued with regard to confidentiality that it is a mechanism for managing feelings of incompetence and the concomitant risk of embarrassment that can arise in everyday social situations, for example, in the encounter between health-care professional and client.<sup>23</sup> We suggest that in the context of suicide, this can be extended further. The ESF Stage 1 questionnaire data show that for some people, part of what it is to experience suicidal feelings is to experience feelings of shame, and of exposure or fear of exposure, which further compound the suicidal feelings. If the experience of shame in suicidal feelings is such that the loss of anonymity in providing identifying details to the researcher constitutes unendurable exposure, that is, that confidentiality is not sufficient to manage the encounter, then anonymity rather than mere confidentiality is a necessary condition for participation.

## **Analysis and ethical implications**

In what follows, we begin by considering the way in which this case was dealt with by the REC, focusing on the concept of risk. We then look at the arguments for retaining a commitment to confidentiality, and for allowing anonymous participation in a study on suicide, framed in terms of the risks rendered invisible by the REC process.

While confidentiality was at the heart of the disagreement with the ethics committee, the process of negotiation also proved to be cumbersome and time-consuming. This in turn raised further ethical difficulties as researchers and participants were left in a state of uncertainty over whether we would be able to continue with Stage 2 of the project.<sup>iii</sup> We conclude therefore by suggesting not only a need for an evidence-based risk assessment, but also the need to consider how the ethics approval process might better fit the qualitative research process.

### **Assessing risk**

According to the Department of Health (DOH):

Researchers must satisfy a research ethics committee that the research they propose will be ethical and worthwhile. The committee has to be assured that any anticipated risks, burdens or intrusions will be minimised for the people taking part in the research and are justified by the expected benefits for the participants or for science and society.<sup>24</sup>

The REC can be understood as carrying out a risk assessment, consisting first, in judging the nature of any risks involved in taking part in the research, and second, in determining whether those risks can be justified when weighed against the potential benefits. While this might seem an appropriate means of ethics review, Haggerty, writing in the context of the Canadian University ethics approval process, argues that the way in which RECs carry out this risk assessment is flawed.<sup>9</sup> Properly understood, risk assessment requires a calculation of the statistical probability of a harm occurring, which in turn requires a calculation based on empirical evidence. Haggerty contends, however, that instead of drawing on empirical evidence, the process of assessing the balance of harms and benefits becomes

a form of decision-making . . . characterized by an attempt to respond to subjectively assessed worst-case scenarios rather than empirical consideration of what is likely or probable.<sup>9</sup>

In other words, probability and possibility are not distinguished and possibility is treated as probability. When the Substantial Amendment for Stage 2 of ESF was considered by the REC, the 'worst-case scenario' was that of someone attempting to or succeeding in taking their own life while participating in or as a result of participating in the research. Indeed, the extent to which the risk was associated with participation and the extent to which it was associated with already being at risk of suicide by virtue of their eligibility to participate in the study were also not clearly distinguished, although the distinction is important, since what is under review is the impact of the research on the participants.<sup>2</sup> More significantly, however, and in line with Haggerty's experience, the risk of a participant's suicide was 'assessed' without regard for the likelihood of this taking place.

Part of the difficulty, then, arises from the lack of empirical evidence informing the REC's decision. As it was pointed out above, there is a lack of research in this area, reflecting a broader need for more empirical evidence that can be used to support decisions made in ethics review, as well as a need to draw more thoroughly on what evidence is available.

However, Haggerty's argument about the nature of 'risk assessment' can be extended further: it is not just that RECs have a tendency to focus on worst-case scenarios, limited only by the extent of the committee members' imaginations; by working in this way, and focusing on imagined but unevidenced harms, there is also a danger of imaginative blindness to other harms and a failure to weigh these appropriately.

Hedgecoe, in his defence of the REC system, suggests that this system is underpinned by the belief that

however well intentioned researchers [are] . . . they are not the best people to decide on the risks and benefits of their research.<sup>25</sup>

Researchers tend to overestimate the benefits and underestimate the risk of harm of their research – hence the need for ethics review. On this model, the REC speaks for the research participant or represents their interests and so tempers the gung-ho tendencies of the researcher. Our contention is that just as researchers might unwittingly and with the best of intentions behave in a way that is unethical, so too might the collective membership of an ethics committee. In particular, harms can both arise from and be rendered invisible by the process of deliberation, by constructing what can be said and by whom.

We now consider what some of those harms might be. First, the question of participant rights and justice and then participant care and safety are considered, and finally the impact on knowledge production.

### *Justice and the right to (equal) participation*

The difficulties inherent in balancing the right to participation against the right to protection are well-documented, as is the tendency of the ethics approval process towards paternalism.<sup>15,17,26,27</sup> The paternalistic remit of the REC is evidenced in the DOH *Governance arrangements for RECs*, where the emphasis is very much on the minimisation of risk. Indeed, while the minimisation of risk is seen as necessary to avoid compromising the ‘dignity and rights’ of participants, the potential conflict between the minimisation of risk, on the one hand, and the dignity and rights of the participant, on the other, is not considered (which is not of course to say that RECs do not consider this possibility). Yet at the same time, while the rights of the participants are not spelled out, and nor is the concept of dignity explored, it is also stated that

selection criteria in research protocols should not unjustifiably exclude potential participants.<sup>24</sup>

While the nature of the commitment to confidentiality is not part of the selection criteria as such, it is material in influencing the choices potential participants make about joining or remaining in the study. It is incumbent on the REC, then, to consider whether denying the right to confidentiality with regard to a suicide plan, and the right to participate anonymously, unjustifiably excludes some participants. By taking a paternalistic approach are they disempowering rather than protecting the dignity and rights of those who might otherwise take part?<sup>17</sup> Furthermore, this can be understood not just as the exclusion and disempowerment of those participants who choose not to remain in the study because they feel that their right to confidentiality and/or anonymity has been compromised, but also of those who choose to continue but are effectively prevented from speaking freely.

Of course, the commitment to confidentiality in research as in other professional contexts usually has specified limits, which can include not only the prevention of harm to others, but also of serious harm to self.<sup>28,29</sup> It is worth noting, however, that in the United Kingdom, it is questionable whether there is a legal right to break confidentiality just because there is a risk of suicide, much less an obligation to do so.<sup>19,30</sup> Here, the distinction between the probability of harm due to the research process and the possibility of a suicide taking place in a group of people who have been selected for the study because they are suicidal comes back into view. That is, the responsibility to minimise the risk of harm associated with taking part in research is not a responsibility to prevent any harm to a participant while they are participating in a study.

It is also illuminating to consider the case of suicide research in the context of qualitative research into criminal activity. Where the researcher is undertaking research with people involved in illegal activities, it is precisely because of what is being investigated that the commitment to confidentiality is maintained even where the participant reveals their own or another’s involvement in crime. There is no general legal obligation in the United Kingdom for researchers to pass on information about a crime, and researchers in this area tend to work within a framework such that there is an ethical obligation to maintain confidentiality precisely because of the possibility of learning about illegal activity on the part of the participant.<sup>6</sup> Indeed, it is unlikely that the researcher’s aims could be met without this commitment. Likewise, in suicide research, just because of the very real possibility that someone will reveal that they are suicidal, confidentiality is maintained precisely in order that the researcher and participant are able to explore the participant’s experience openly and truthfully. While this might seem paradoxical insofar as research aimed ultimately at suicide prevention stops short of forcibly trying to prevent a suicide, it is not a case of the researchers doing *nothing* to help prevent a suicide, but setting limits to what they will do *without the participant’s permission*.

### *Confidentiality and participant safety*

The nature of the relationship between researcher and participant, and the way in which each understands this relationship, raises a further question regarding the risks associated with limiting confidentiality. That is, it is not obvious that breaking confidentiality is the most appropriate means of minimising the risk of suicide, so that even leaving aside the question of justice and taking the concerns of the REC on their own terms it remains to be asked, what is the impact of limiting confidentiality in this way on participant safety?

In medical ethics, in addition to arguments based on individual rights or deontological principles such as respect for autonomy, there is a *prima facie* argument for maintaining confidentiality on the grounds that without a commitment to confidentiality, patients may not be sufficiently trusting to reveal vital information, thus undermining the ability to deliver care.<sup>18,31,32</sup> This also applies in the context of research. Not only is there a need for trust in order for the participant to reveal information vital to the study, but also to give the researcher the best chance of responding appropriately where the participant is at risk. Thus, the research design for ESF includes a clear protocol to be used by the researchers to respond to participants where they are perceived to be in distress or become suicidal during an interview. This involves responding according to the level of risk or intensity of distress: at the lowest level, this would mean, for example, taking a break and focusing on positive aspects of the participant's life, progressing to talking to participants about contacting their formal and informal support network, and at the highest level, offering to accompany the participant to the hospital or persuading them to allow the researcher to call an ambulance.<sup>11</sup> Where the participant feels that to reveal their distress or intention to take their own life would be met with the decision to break confidentiality without their consent, they may choose not to be open with the researcher, instead presenting a 'face'. This in turn makes it far more difficult for the researcher to detect distress and suicide risk, and therefore to respond in a way that is helpful and maintains the trust between researcher and participant.

### *The impact on knowledge production*

Halse and Honey have a broad definition of a 'research participant', to include all those who are involved in or impacted by the research:

the assortment of particular and generalized others connected with any research site/s and any group of research subjects, including the researchers themselves.<sup>33</sup>

The ethics of research is therefore also broadened. However, it is argued that while ethics committees and their guiding principles pay lip service to the need to take into account this wider community of participants (recall here that the REC is asked to balance the risks to the research participant not just against the benefits to participants, but also to 'science and society'),<sup>24</sup> in practice, the focus tends to be on those participants who are also the 'subjects' of the research. Again, this is at least in part a function of the medical model, with the emphasis on formalised procedures for protecting participants, which in turn can only be administered to the particular participants directly involved in the research. This, together with the method of 'risk assessment' employed, obscures from view the wider ethical issues, including the way in which the ethics approval process constructs research design.

Restricting who speaks and what can be said in suicide research not only raises questions of safety and justice at the microlevel of the particular research participant, therefore, but also impacts on what can be known and understood about suicide, further impacting on safety and justice at the macrolevel. Just as the tendency to exclude people who are suicidal from clinical studies has a negative impact on the development of treatments,<sup>12,34</sup> so too does restricting qualitative research where the aim is to facilitate the detection and



mitigation of risk of suicide through empathic understanding. In undertaking a risk assessment, therefore, it is important to take into account the way in which a decision to restrict confidentiality determines who is and is not heard in suicide research (including the researchers), and what this means for the way in which societies understand and respond to suicide.

### **Ethics review, ‘risk assessment’ and qualitative research**

Whether or not there is a bias against qualitative research on the part of RECs is debated.<sup>8,25</sup> What this analysis suggests is that whether or not there is a bias against qualitative research as such, it is in the nature of qualitative research that it is more difficult to specify in advance precisely what it will involve, both in terms of content and the subjective responses of participants, and therefore to determine what the risks of harm might be. This in turn means that it is much more likely to be disadvantaged by the process of ‘risk assessment’ described above, which appeals to ‘worst-case scenarios’ rather than evidenced risks. In the case of suicide research, where the possibility of a participant taking their own life is undoubtedly a real possibility, the ‘worst-case scenario’ is indeed among the worst of scenarios.<sup>iv</sup> However, this makes it even more incumbent upon the researchers and committee members to disentangle possibility from probability and to consider the impact of curtailing the research.

It is perhaps understandable that RECs veer towards paternalism when dealing with suicide. At the same time, the reluctance to engage in qualitative research in this area also perhaps reflects the wider societal reluctance to talk openly about suicide, ironically one of the reasons why there is such a need for qualitative research in order to facilitate understanding and to give those who have suicidal feelings a voice. At the very least, there is a need to consider the breadth of risks when making decisions of this nature, and to consider evidence regarding the likelihood of those risks, which is in turn informed by listening to those with relevant experience.

In this respect, the question of voice also arises with regard to the process of ethics approval itself. As was pointed out above, the REC is charged with weighing the benefits and burdens of a research proposal. This weighing of burdens against benefits, however, is not a simple utilitarian calculation. If it were, then considerable risks and burdens might be permitted for the sake of a very great good. This, in part, is what codes of research ethics are designed to protect against – that the good of the few is not sacrificed for the greater benefit of the many; and in general, it is protected by means of a principle of informed, voluntary consent. The principle informing the process of deliberation of the REC is perhaps better understood on a Kantian model; the committee is charged with protecting the dignity and personhood of the participants.<sup>35</sup> Extending this model, the work of the REC might be seen as a discursive, democratic form of decision making that derives its legitimacy from its procedural form. Garrard and Dawson support this view, claiming that the authority of the REC

comes from the fact that the REC consists of a diverse group of experts (including lay expertise), reaching agreement through discussion and consensus.<sup>27</sup>

If the legitimacy of the REC rests on the expertise of its members and the process of deliberation that they undertake, then this legitimacy is undermined if, through this process, the voice of those they are charged with protecting and representing is silenced or subdued.

One way in which this might be addressed is by more direct representation of participants at a committee meeting, where currently they ‘speak’ only through the REC members and the researchers, largely at the discretion of those who are present.

The DOH states that

RECs should collaborate with ... actual and potential research participants.<sup>24</sup>

However, it appears that research participants have very little direct say in the decisions that RECs make and little opportunity to represent their own best interests.<sup>17</sup> In the case of participants perceived as vulnerable, this compounds a broader tendency to base decisions on historical assumptions rather than participants' own assessments or empirical evidence.<sup>14,36</sup>

The application form for NHS ethics approval does include a question about public involvement with the research, which might include consultation with potential participants in the design of a study. However, recent research shows that a majority of applications fail to demonstrate this, suggesting that RECs need to do more to ensure that researchers both understand and facilitate public, including participant, involvement.<sup>37</sup>

Of course, in most cases it is not possible to involve actual participants since approval must be given before the study begins.<sup>v</sup> However, insofar as there are practical obstacles to participants' direct representation, this further suggests a need for more research into the experience of research participation such that this can at least inform those who claim to speak for participants, whether researcher or committee member. More radically, it might indicate the need for a rethinking of the way in which ethics approval is carried out.

## The process of qualitative research and the process of ethics review

Given the ongoing and emergent nature of qualitative research, it is to be expected that the ethical aspects of qualitative research will also be ongoing and emergent. For example, the difficulties in ensuring adequately informed consent at the beginning of a study suggest that continued consent cannot be assumed but must be regularly revisited, with participants reminded of their right to withdraw. As such, it has been argued that the ethical framework developed in the context of medical research is inadequate for qualitative research and instead what is required is an approach that has been termed 'ethics-as-process'.<sup>4,8,36</sup> That is, ethical issues are attended to throughout the course of the study, both anticipated and unanticipated, rather than viewed as a one-off event to be dealt with at the beginning or even as a series of formal, predictable events. This also means that qualitative research requires a particular kind of moral attention on the part of the researcher in order to discern and respond appropriately to ethical issues as they arise.<sup>38</sup>

The 'ethics-as-process' model has been developed to match more closely the process of qualitative research, but how might the ethics approval process be developed better to match both? To begin with, it would seem to require less focus on the unevidenced risk of worst-case scenarios, and greater attention to ethics as ongoing and unpredictable, and because of this, to the moral competence of the researcher. This might suggest a formal requirement for the inclusion of committee members with specific expertise in ethics, based on a shared understanding of what ethical expertise consists in (and in order to avoid circularity, it would have to consist in something other than membership of an ethics committee). In addition, given that ethics is no longer to be understood as something that can be dealt with prior to the commencement of a study, the involvement of the REC also needs to be ongoing,<sup>8</sup> which in itself would help to attune REC members to the everyday ethical moments in research, rather than these being obscured by a focus on hypothetical 'red letter dilemmas'.<sup>39</sup> Indeed, the reciprocity involved in an ongoing relationship between researcher and reviewer would help to develop the ethical attunement of both. It would also open up the possibility of involving participants in the process, for example, through feedback gathered by the researchers or submitted online.

## Conclusion

There is a relative lack of qualitative research into suicide and a need to redress this. It is therefore essential that researchers and RECs work together to facilitate this, in a way that is ethically defensible. The above analysis suggests that insofar as the REC is tasked with carrying out a risk assessment, this must be

adequately informed by the available evidence. Where that evidence is lacking, further research into the ethics of research, in particular into participants' experiences of taking part, is required.<sup>17</sup> This would also provide a means for allowing the participants' voices into the ethics approval process. Some consideration of how participants can be represented further would also be advantageous. Since the existing approach to ethics review inevitably limits the extent to which participant representation can be achieved, and further, does not currently provide a good fit with the qualitative research process, there is a need for a reconsideration of how ethics review takes place.

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### **Conflict of interest**

The authors declare that there is no conflict of interest.

### **Notes**

- i. While this article focuses on the process of NHS ethics review in the United Kingdom, a survey of the literature suggests that the relevance of the analysis extends beyond the context of the United Kingdom and of health research.<sup>9,33,36,40,41</sup>
- ii. Usually, a Substantial Amendment is submitted by the researchers where the direction of the research changes substantially following the initial ethics approval. The request by the REC for a Substantial Amendment might be understood as an attempt to use the existing system to accommodate the ongoing ethical demands of a qualitative study and some of the difficulties encountered to be a result of the inadequacy of this approach.
- iii. Our approach was to keep participants informed and to invite their feedback, including consulting participants on the decision to concede to the REC's request for a change to the confidentiality statement. We would like to thank our participants for their support and for their feedback, which also helped to guide the analysis presented in this article.
- iv. This requires qualification. It might be assumed that this is the view taken by most people who are not suicidal. However, it is certainly not the view of some of our participants, who do not consider death, including death by suicide, to be the worst-case scenario, either for themselves or as a rational response for anyone who considers life not to be worth living.
- v. Thanks are owed to Ann Gallagher for helping to clarify this point.

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